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# Interventions that Support Caregivers of Veterans with Traumatic Brain Injury: A Systematic Review

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Interventions that Support Caregivers of Veterans with Traumatic Brain Injury: A  
Systematic Review

by

Melissa J. Franzen

MSW Clinical Research Paper

Presented to Faculty of the School of Social Work  
St. Catherine University and University of St. Thomas  
Twin Cities, Minnesota

Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

### **Abstract**

The problem is that many caregivers face isolation, depression and ambiguous grief in caring for a veteran with a TBI. Previous research has indicated that there are challenges that caregivers face in caring for a veteran with a TBI. A systematic review was done to answer the question, what are the effective social work practices for caregivers with a veteran who has a Traumatic Brain Injury (TBI). Articles were reviewed from the timeframe of 1997 to 2015. These articles covered TBI, veterans, caregivers, military populations and civilian populations. From the research, there were six social work treatments and four interventions that were identified. The social work treatments are TBI Case Management, TBI Schematic Therapy, Multifamily Group Treatment (MFGT), Brain Injury Family Intervention (BIFI), Loss and Grief Intervention and Marriage and Family Therapy. The social work interventions that were used in most of these social work treatments were education, therapy, loss and grief and transitional care. Even though many of these treatments may appear to work with both populations, the social work needs to recognize and address military culture and the differences between military and civilian culture. However, there is little or no qualitative or quantitative studies or long-term studies on how effective these social treatments and interventions are. Further research needs to be done to see if what is currently being used in social work is effective help for caregivers who care for a veteran with a TBI.

*Keywords:* TBI, Caregivers, Social Work Treatments and Interventions

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## **Introduction**

Traumatic Brain Injury (TBI) affects the majority of veterans that have been deployed to OEF (Operational Enduring Freedom) and OIF (Operational Iraq Freedom) (Ramchand et al., 2014). TBI is a common injury and is known as the “invisible injury” among veterans from the Army, Navy, Marines and National Guard Reserve (French, Parkinson, Massetti, 2011). Because of the medical advances in the past two decades, more veterans are surviving a TBI (Brzuzy & Speziale, 1997). As a result, veterans with a TBI need additional support from a friend or family member. These informal caregivers assume responsibilities of caring for a veteran with a TBI while often experiencing their own challenges. This study will explore social work practice interventions designed to support the informal caregivers of veterans living with TBI.

## **Supporting Veterans with TBI**

TBI is an injury to brain tissue that results in loss of consciousness, skull fracture or posttraumatic amnesia (Hanks, Rapport, Vangel, 2007). Veterans serving in the line of duty may incur a TBI through such external forces as blasts, falls, motor-vehicle incidents and assaults (Moore, 2013). However, some of these incurred injuries can also result from accidents while not serving in the line of duty (Moore, 2013). TBI may present an array of the following symptoms: Physical changes such as auditory, speech and visual impairments, behavior changes such as impulsivity, regression, anger, aggression, frustration, depression and anxiety and cognitive changes such as difficulty concentrating, forgetfulness, poor judgement and communication difficulties (Patel, 2015). Some other general symptoms that show up in

veterans with a TBI are headaches, dizziness or sleep problems (Carlson, Nelson, Orazem, Cifu, Sayer, 2010).

TBI can also mimic other mental illnesses. For example, individuals who have been diagnosed with TBI have experienced diminished cognitive, physical or behavior functioning, most notably when the veteran is tired. These same symptoms can be mistaken for depression (Sable & Osborne, 2012). Another example would be that those individuals who have been impacted by TBI display fluctuations in moods, which could be mistaken for bipolar manic episodes (Sable & Osborne, 2012). In April 2007, the VA initiated screening techniques that can assist in detecting if a veteran has a TBI (Carlson et al., 2010). The screening tool is a series of questions that are asked of Iraq and Afghanistan veterans. The questions asked are related to exposure to blasts, symptoms that occurred after being exposed to blasts and the severity of the symptoms (Carlson, et al., 2010). This screening tool helps to distinguish a TBI from mental illness. Although veterans with mild TBI have some challenges, the focus of this study is on veterans with moderate to severe TBI since these veterans have more challenges and needs for long-term care (Carlson et al., 2010).

**Post-Traumatic Stress Disorder.** Post-Traumatic Stress Disorder (PTSD) is another mental illness that can accompany TBI affected veterans. PTSD is experiencing a traumatic event such as war or combat, terrorist attacks, domestic violence or a serious injury (Ghaffarzadegan, Edrahimvandi & Jalali, 2016). PTSD symptoms such as depression, anxiety, memory, sleep problems and emotional disturbances (such as anger) are similar to TBI symptoms (Chen, 2011). Veterans returning from Iraq and Afghanistan with a TBI display symptoms of PTSD three to twelve months after the TBI diagnosis (Chen, 2011). The percentage of veterans having both TBI and PTSD is 48%. “Battlefield PTSD” is not easy to

detect; the only way to detect it is by cognitive personality testing (Chen, 2011). There is a particular part of the brain called the “amygdala” which regulates emotional processing. If this area of the brain is affected, it will play a significant role in the veteran developing PTSD (Chen, 2011). In addition, veterans with both TBI and PTSD have diminished functional capabilities and more intense PTSD symptomology (Patel, 2015). Lastly, longitudinal symptoms of OEF and OIF veterans who were dually diagnosed with TBI and PTSD showed latent worsening (Patel, 2015). Thus, symptom severity may not be initially apparent to those working with veterans (Patel, 2015).

Because of the trauma to the brain, veterans with moderate to severe TBI that have PTSD can have a complicated bio-psycho-social recovery course resulting in the involvement of multiple professionals and interdisciplinary teams. They may need neurologists, speech therapist, physical therapist and mental health providers depending on the severity of the TBI (French et al., 2011). Eventually, these veterans with a TBI are released from around the clock multiple health care providers and are transitioned into the care of informal friends and family caregivers. These informal caregivers are in the position of being responsible with no training for the ongoing care that is needed for the veteran with a TBI.

### **Caregivers of Veterans**

Caregivers are defined as spouse, parent or sibling. Since 9/11 there are 1.1 million caregivers assisting veterans (Ramchand et al., 2014). The cost of the care that these caregivers provide is estimated at 3 billion dollars a year and 59% of these caregivers do not receive any support services such as therapists, group therapy and TBI case management (Ramchand et al., 2014). Some of the initial issues caregivers face are changes in the veteran, grief and loss, demands of caretaking, financial burdens, stigmas in the military around TBI and their own



psychological needs (Patel, 2015). These caregivers are faced with responsibilities and barriers in care which impact their own well-being and their care for the veteran with a TBI.

**Responsibilities.** Caring for the veteran with a TBI generally shifts from institutionally provided care to informal unpaid family care (Ramchand et al., 2014). This type of care may be short-term or long-term depending on the extent of the TBI with the veteran. Caregivers' responsibilities include helping with emotional issues, navigating health care, accessing benefits, finding legal counsel, making medical appointments, managing pain, working with them in therapy, and assisting with aided devices the veterans may need (Griffin et al., 2012). A common responsibility among caregivers is that 95% of the time caregivers are aiding and managing behaviors or regulating moods of veterans with TBI. (Petersen, 2015; Tam, 2015).

**Barriers.** Caregivers face many barriers. These barriers include denial that the veteran has a TBI, stigmas around this disorder or concerns about employment and financial repercussions (O'Donnell, Begg, Lipson, 2011). Other barriers arise from working with interdisciplinary teams. Interdisciplinary teams may be comprised of multiple health professionals helping the veteran with TBI and it can be challenging to coordinate care for the veteran (Patel, 2015). Furthermore, communication between the multiple professionals and the veteran about the care can be stressful, in addition to the day to day care of the veteran with a TBI (Patel, 2015).

**Impact to caregiver.** Caregivers are psychologically impacted while caring for a veteran with a TBI. A caregiver's well-being is affected daily by the demands and stress of caring for a veteran with TBI. Research shows that 47% of families reported increased distress, 32% reported increase in anxiety and 23% reported depression (French et al., 2011). In the initial stages of the TBI diagnosis, adjustment can be difficult for the veteran and the caregiver. In the

early stages of diagnosis, caregivers may experience shock, anger, confusion and helplessness (MacFarlane, 1999). Later the caregiver may feel elation and a sense of hope and optimism (MacFarlane, 1999). After the caregiver has settled in doing long-term for a veteran, the “mourning stage” sets in with the caregiver (MacFarlane, 1999). Because of the cognitive rupture, the veteran may not return as the same person as before (Stranberg, 2009). At times, caregivers may feel like they are living with a stranger and they have lost their loved one because of how the TBI affects the veteran’s personality. This could pose “ambiguous grief” for the family members (MacFarlane, 1999).

### **Military Culture**

Military caregivers, compared to non-military caregivers, face more stress (Patel, 2015). Some reasons why military caregivers face more stress are that they are faced with more complex issues, they are younger, they may have children, and will be providing longer term care compared to non-military caregivers (Patel, 2015). Military culture plays important factor with care for the veteran and caregivers. This culture can impact the veteran in getting care and the caregiver in dealing with the veteran. Within the military culture, the stigma of mental health impacts veterans with TBI, especially those with mild to moderate symptoms. For example, if the veterans were not treated initially for a TBI, they may not realize that they have a TBI. However, if the veterans have a TBI, they may try to conceal that information from medical or mental health professionals (Patel, 2015). The reason veterans may conceal their TBI diagnosis is their fear of judgement from their commanding officer or their unit. A recent statistic showed that 59% of army personnel and 48% of marines were concerned their superiors would discriminate against them if they were diagnosed with mental health conditions or TBI (Patel, 2015). In addition, veterans with TBI may face the stigma of being regarded as “crazy” or a

“ticking time bomb” (Chase, Mc Mahon, Winch, 2016). These stigmas add challenges not only for the veterans but for the informal caregivers who are caring for the veterans with a TBI.

### **Caregiver Burnout**

Another challenge the caregivers face in caring for a veteran is burnout. Research indicates that those who assist others that have survived trauma may be at risk for “burnout, compassion fatigue and vicarious trauma” (Phelps, Lloyd, Creamer, Forbes, 2009).

Symptomology of burnout is feeling emotionally and physically exhausted, feelings of hopelessness and helplessness, depression, reduced insight and decision making (Phelps et al., 2009). In addition, burnout is the result of being emotionally burdened beyond one’s own capacity (Phelps et al., 2009). Similar research says burnout can appear physiologically, showing up in helping relationships as chronic physical and emotional fatigue, depletion of compassion or empathy, boredom, cynicism or depression (Diaconescu, 2015). However, burnout affects more than just empathy and compassion; it affects other areas such as the overall well-being of the caregiver.

Burnout was originally studied and defined in relationship to employment and work related stressors within the human service industry (Katsifaraki & Wood, 2014). Today, burnout is being considered with caregivers and especially caregivers of veterans with TBI. In addition, there has been an increase in research of burnout from the 1970’s, which focused on professional human services (Katsifaraki & Wood, 2014). Currently, burnout is recognized in any type of long-term care that is provided (Cheng, 2005). Furthermore, the challenges for the caregivers can be physical and mental especially in scenarios where the veteran needs care with behavior and emotional challenges. Managing these challenges can affect the caregivers’ well-being, which in turn impacts the veteran with a TBI. The factors that elicit burnout for caregivers of a

veteran with a TBI are isolation, poor communication from other professionals or lack of expertise in handling challenges with a veteran with TBI (Katsifaraki & Wood, 2014). If the caregiver is burned out, it affects the quality life for the caregiver and the veteran with a TBI.

**Prevention of burnout.** There can be preventive measures for burnout that caregivers may use as self-care in order to provide adequate long-term care for veterans. The term “mental hygiene” is a term to define a way to help an individual cope and be aware of self-care needs in order to prevent burnout (Katsifaraki & Wood, 2014). Three areas have been identified to help prevent: physical or behavioral strategies, relational strategies and cognitive strategies (Diaconescu, 2015). Physical strategies include exercise, meditation or simple relaxation techniques. Relational strategies include expressing feelings in relationships with friends, family, or a therapist. Finally, cognitive strategies include deliberate distraction like watching movies, listening to music or surfing the internet (Diaconescu, 2015). Thus, this study will examine caregiver burnout, use of prevention strategies and the impact on the well-being of caregivers caring for veterans with a TBI.

### **Conceptual Framework**

Caregivers help with the multiple facets of care for veterans with a TBI such as assisting with physical, cognitive and emotional needs. Because of the amount of care required, the family functioning level can be abruptly and sustainably altered indefinitely (Chronister, et al., 2016). Person-in-environment theory is understanding the individual’s behavior that is impacted by their own environment (Kondrat, 2002). This theory is applicable to caregivers who give informal care to veterans with TBI. The two parts of this theory which are especially applicable are “human agency” and “social structure” (Kondrat, 2002). The human agency refers to the caregiver and is defined as to what capacity a person has to make a difference with the current

situation (Kondrat, 2002). The social structure refers to the family structure and is defined by rules and resources that are a part of the social systems and institutions (Kondrat, 2002).

Caregivers having to give constant care to the veteran with a TBI may experience elevated levels of stress, burden and depression (Dengenffe & Bursnall, 2011). In addition, caregivers are impacted financially by limited income because the caregiver may not work full-time and socially impacted because lack of knowledge and understanding from friends or other family members who do not recognize the “invisible injury” of a TBI (O’Donnell et al, 2011). Furthermore, the family is disrupted because their roles of responsibility have changed since veteran may not be able to function in the family the same way as before the accident.

Person in environment theory will guide this research by enabling the researcher to look through the lens of the caregiver and to recognize the new environment the caregiver has to navigate with the veteran that has TBI. Secondly, further research in this project will identify, assess and examine social work practices or interventions and how they support the caregiver.

### **Purpose & Research Question**

This systematic research project will examine effective social work practices in supporting families or caregivers that are providing supportive services for a veteran with a TBI. The purpose of this study is to investigate what treatments are available, how social work practices are used and what are the results. Consequently, the research question is: What are the effective social work practices that support caregivers of veterans with TBI?

### **Methods**

The purpose of this systematic research project was to explore the question: what are the effective social work practices that support caregivers of veterans with Traumatic Brain Injury (TBI)?

For this study, terminology and word choice of Traumatic Brain Injury (TBI) and Brain Injury (BI) were used for research criteria. Caregivers or families were also both included in research criteria. Military studies were initially examined first in relationship to this topic. However, there was limited research on military caregivers. Civilian studies on caregivers were reviewed to examine if they met the criteria of TBI or Brain Injury, caregivers or families, social work practices and interventions. Another criterion that was considered was types of social work practice that involve TBI patients and caregivers.

This research project explored what social work practices were available for TBI care for caregivers and TBI patients, what interventions were used to support caregivers and TBI patients and how effective were the social work practices and interventions for caregivers who care for someone with a TBI. The study considered caregivers or families, social work, social work practices, interventions, group therapy, individual therapy, if there were any studies on the social treatments or interventions and how long these studies were done after implementation of these practices.

### **Types of Studies**

To answer the question of what are the effective social work practices that support caregivers of veterans with TBI, a range of studies were reviewed on caregivers with individuals with TBI, social work practices with TBI care and care of veterans with TBI. Systematic, single

studies, qualitative and quantitative studies were considered. The focus on the study was caregivers' experiences with individuals who have a TBI, social work practices that help individuals with TBI and their caregivers. Lastly, the research available about this topic was mainly focused on the acute care in social work practice for caregivers who cared for someone with a TBI. Furthermore, there was insufficient research available with longitudinal studies.

### **Search Strategy**

The preliminary search of academic journals and online search sites looked at SocINDEX, PsycINFO, PILOTS, Military Publications (RAND), Social Work Abstracts and Academic Search Premier. There were no systematic reviews addressing the question of social work supports for caregivers of veterans with a TBI. To understand the scope of available literature on this research question, a search time line was done from 2000-2015. Specific terms of families or caregivers, TBI or BI and veterans were considered to capture peer-reviewed literature that would address the research question.

### **Review Protocol**

Peer-reviewed, full-text articles were used. Since there is not a lot of literature on effective social work practices that support caregivers of veterans with TBI, social work practices that support caregivers in the civilian populations were reviewed. Also, TBI care is a new social issue that has been only addressed in the military since 2001. Articles were found using the search criteria of PsycINFO, Academic Search Premier, SocINDEX, Social Work Abstracts and RAND military academic publication. These data qualifications were put in place to address the credible research.

**Inclusion criteria.** Under Academic Search Premier included PsycINFO and SocINDEX, searches that were used using terms (families or caregivers), veterans, traumatic

brain injury, brain injury, military, interventions and social work. Other databases considered are PILOTS and PubMed. The articles that came up had a timeline of 1997 to 2015. The focus point of this research was to assess the existence of social work practices that involved TBI and caregivers or families. Articles were included that discussed caregivers mental health around TBI for both military and civilian populations. In addition, articles outside the US were reviewed regarding caregivers and mental health with TBI. If the topics were transferrable to military social work with TBI caregivers, they were considered as part of the research.

**Exclusion criteria.** Of the 47 peer-reviewed articles that met the initial search criteria, only 13 met criteria to be included in this research project. Articles that were excluded for research review covered: studies focusing on partnership caretaking, broad perspective of diagnoses, redundancy of covering same topic information, focus on veterans with TBI, not enough study evidence on caretakers and lack of longitudinal studies on caretakers.

Inclusion and exclusion criteria decisions were made based on the titles and the abstracts of the peer-reviewed articles. The final review consisted of 13 peer-reviewed articles. See Table 1 for a complete list of included articles. A more detailed list of included articles with the summary of content can be found in Appendix A.

Table 1

*Included Articles*

Database	Title	Authors
PsycINFO	Adults with Acquired Traumatic Brain Injury: Experiences of a changeover process and consequences in everyday life	Strandberg, 2009



Database	Title	Authors
SocINDEX	Mild traumatic brain injury: implications for social work research and practice with civilian and military populations	Moore, 2013
	Caregivers of veterans with “invisible” injuries: What we know and implications for social work practice	Patel, 2015
	Treating brain-injured clients and their families.	MacFarlane, 1999
	Trauma Spectrum disorders: Emerging perspectives on the impact on military and veteran families	O'Donnell, Begg, Lipson, Elvander, 2011
	Care Coordination in Military Traumatic Brain Injury	French, Parkinson, Massetti, 2011
	Caregiving and Traumatic Brain Injury: Coping with grief and loss.	Petersen & Sanders, 2015
	Basic training for building a program in military social work.	Sable & Osborne, 2012
	Quality of professional services following Traumatic Brain Injury: Adult sibling perspectives.	Degeneffe & Burnsall, 2015

Database	Title	Authors
Academic Search Premier	Psychiatric diagnoses among Iraq and Afghanistan war veterans screened for deployment-related traumatic brain injury	Carlson, Nelson, Orazem, Cifu, Sayer, 2010
	Tell Me What You Don't Remember": Care-Seeking Facilitators and Barriers in the Decade Following Repetitive Blast Exposure Among Army Combat Veterans	Chase, Mc Mahon, Winch, 2016
	The experience of challenging behaviours following severe TBI: a family perspective	
	Caregiving appraisal after traumatic brain injury: The effects of functional status, coping style, social support and family functioning.	Tam, 2015
		Hanks, Rapport, Vangel., 2007

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### **Research Synthesis**

The purpose of this systematic literature research was to explore the question: what are the effective social work practices that support caregivers of veterans with Traumatic Brain Injury (TBI)? The databases used for this research were PsycINFO, SocINDEX, PILOTS, Social Abstracts, RAND (military publication) and PubMed. From these databases, 11 articles met the criteria of Traumatic Brain Injury, Interventions, Treatments, Social Work Practices, Family, Caregivers. Out of the 11 articles, 4 were focused on treatments for military families and the other 7 articles were focused on treatments with civilian populations.

Timeframes that were used for this research focused on articles from 1999 to 2015. Four articles used OEF and OIF veterans, TBI, caregivers and families. The remaining used civilian, TBI, caregivers and families with a few articles mentioning transitional care for veterans in civilian social work. Also, there was an insignificant amount of qualitative and quantitative data done about the impact social work interventions had on caregivers with a veteran or civilian who had a TBI. All 11 articles touched on what is TBI, physical aspects of TBI, “significant injury”, and implications to the social work field of survivors with a TBI and their caregivers (Patel, 2015).

A quarter of the research involved articles on military social work theory frameworks and the other half were on civilian social work theory frameworks. In the research, either synthesized research or single case study research was used. The social work treatments included TBI Case Management, TBI Schematic Therapy, Multi Family Group Treatment (MFGT), Brain Injury Family Intervention, Coping with Grief and Loss Intervention, and Marriage and Family Therapy. These social work frameworks used both military and civilian populations. From these social work treatments, themes of therapy, education, loss and grief and transition care emerged.

Although the literature discussed how social work treatments were used with caregivers there was no data to support the effectiveness of these social work treatments. However, each of these social work treatments each used the reoccurring themes of interventions used that included education, therapy and transitional care for TBI patients and their families; and TBI veterans and their families.

### **Thematic Analysis**

Traumatic Brain Injury (TBI) Case Management, TBI Schematic Therapy, Multi Family Group Treatment (MFGT), Brain Injury Family Intervention (BIFI), Coping with Loss and Grief Treatment and Marriage and Family Therapy are social work treatments that address the caregivers' burdens, depression and loss and grief. Most of these theory treatments were built on models of mental health or dementia models. Also, these social work treatments used similar social work interventions such as therapy or counseling, education, addressing loss and grief for caregivers and transitioning long-term care for TBI patients and caregiver, which are themes that emerged from the literature. Lastly, the social work interventions are used for both military and civilian caregivers who have a loved one with a TBI. Furthermore, these social work treatments will be discussed in the next following sections.

### **TBI Case Management**

The first social work treatment is TBI Case Management, which involves an individual that is either a nurse or a social worker who has specific training in TBI (French et al., 2011). French et al., (2011) state that TBI Case Management helps the veterans with TBI, families and caregivers. The TBI Case Manager helps coordinate the appointments and scheduling of multiple professionals who are involved in the care for the veteran with a TBI. Depending on the impact of the TBI, these multiple professionals can consist of speech therapists, physical

therapists, a specialist that deals with amputees, doctors, nurses and neurologists. TBI Case Managers also explain medical terminology and ensure that the patients are heard and understood when facilitating communication between patients and providers. One of the priorities in the treatment plan is to ensure that the needs of the veteran with a TBI are met. If the treatment plan is not working, the case manager reevaluates the plan and implements and monitors a revised treatment plan, if necessary. Another facet the TBI Case Manager helps with are referrals for the veteran, caregiver and families outside the VA after initial treatment since many of the resource referrals may not be in close proximity to the VA. Lastly, the TBI Case Manager provides education, psychosocial support, military system care and clinical support for caregivers and families.

### **TBI Schematic Therapy**

TBI Treatment Schematic Therapy is another social work treatment plan that addresses the new role of the veteran in the family and helps the family adapt to the transition. According to Laroi (2000), after a TBI, family modification change is needed in order to help the family assimilate to the change in the veteran because of the stressors and role changes that occur. The focus is on easing the TBI patient into the family dynamics and roles within the new family structure. The therapist listens carefully to what the TBI patient has to say and allows for the TBI patient to be heard by others. By doing this, the therapist is helping give credibility to the TBI patient. The therapist may amplify what the TBI patient is saying by pointing out to other family members the effects of the behavior on the caregiver and offering suggestions. How the TBI person is accommodated depends on the family system, its adaptability and flexibility. Furthermore, the clinician needs to be aware of how the family operated before the injury and

before family therapy. Family therapy focuses on aspects of counseling, support therapy, education transitional care and family training.

### **Multifamily Group Treatment**

A third social work treatment is MFGT, which was originally a treatment plan for families who had a family member with a serious mental illness and has now been modified for families with a TBI member (Perlick et al., 2011). Perlick et al., (2011) explain that these MFGT involve sessions that are biweekly group meetings for the family. The treatment plan focuses on helping families improve coping skills, managing illness and developing skills for preventing relapse (Straits-Troster et al., 2013; Perlick et al., 2011). In addition, a tool the therapist uses is ecomaps which highlight and identify family supports, types of connections, diversity, stability and additional resources. This information helps the clinician assess the strengths and weaknesses within the family social network. The MFGT also addresses education, skills training and formulation, which is part of the treatment plan.

### **Brain Injury Family Intervention**

BIFI is another social work treatment plan that focuses on the family and adjustments of having a person with TBI (Kreutzer, Stejskal, Godwin, Powell, Arango-Lasprilla, 2010). This social work practice incorporates five sessions and it has an interactive format that addresses issues, problem solving and goal setting (Kreutzer et al., 2010). Each of these sessions lasts 90 to 120 minutes long with two or three topics covered in each session (Virginia Commonwealth University, Family Support Research, n.d.). Topics in these five sessions also cover goals, solving problems effectively, learning how to better manage stress and intense emotions and self-care (Kreutzer et al., 2010). In addition, the BIFI meets six primary goals of effective whole family rehabilitation (Virginia Commonwealth University, Family Support Research, n.d.).

These objectives are providing patients, families and caregivers information about symptoms and challenges with a brain injury and helping caregivers and families understand the effect on the person with a TBI (Virginia Commonwealth University, Family Support Research, n.d.).

Kreutzer et al., (2010) explain that other areas in the session cover how it affects the family as a whole, teaching the family and caregivers TBI strategies, problem solving, teaching coping strategies that help the emotional recovery of the TBI patient and helping family members feel better about themselves and their relationships. Lastly, the other sessions provide hope, identify strengths, help access community resources and teach communication skills for long-term support for families and caregivers (Virginia Commonwealth University, Family Support Research, n.d.).

### **Coping with Grief and Loss Intervention**

The social work frame treatment of Coping with Grief and Loss Intervention focuses on education with loss and grief and gives support to caregivers who care for a loved one with TBI (Petersen & Sanders, 2015). The foundation of this group was derived from educational groups with Dementia (Petersen & Sanders, 2015). Petersen & Sanders (2015) state the purpose of this group is to provide education about TBI, address loss and grief and identify coping strategies in a supportive environment. Before anyone attends, there is a screening process caregivers must undergo to ensure they are ready to address the grief and loss. The screening consists of a series of open-ended questions about their loss, coping strategies and openness to receiving and giving feedback to others. The group meets weekly for five days in five consecutive weeks. The meetings last approximately two hours long. The group facilitators are comprised of a social worker that lead the group and second social worker or “experienced family member” (Petersen & Sanders, 2015). Petersen & Sanders go on to explain that after the session, a follow up

meeting is scheduled a month later. In the curriculum, there are readings, videos, addressing and incorporating self-care, journaling assignments after each session for the attendees. The purpose of the specific curriculum is to aid caregivers in their process around grief and loss and help them establish healthy coping strategies. This social work treatment also uses education, therapy and transitional care.

### **Marriage and Family Therapy**

The last social work treatment is Marriage and Family Therapy. MacFarlane (1999) states that marriage and family therapy is quite applicable in working with the TBI patient, caregiver and families, which is the last social work framework. The intervention approach addresses the specific traumatic event that affects the marriage or family dynamic. One aspect the therapist will address is the grief stages that happen for the caregiver and family members. The grief stages do apply the caregiver as the initial shock wears off and the caregiver comes to terms that their loved one is no longer the same person. One of the barriers that gets in the way of treatment is that the family member should feel grateful. Other feelings accompany this such as guilt and anger. Another area the therapist addresses is stages of adjustment. These stages are shock, elation, reality and mourning. The adjustment stages have some common symptoms that are shared with the grief stages. MacFarlane (1999) intermingles both of these stages to address the types of feelings, experiences that a caregiver may go through with a loved who has a TBI. The therapist facilitates the last stage of adjustment “mourning” (MacFarlane, 1999). MacFarlane (1999), explains that the therapist validates the families experience with loss. Finally, the therapist helps the caregiver and family rebuild their lives and let go of guilt and anger. In the therapy session, the therapist also focuses on accessing support within the community such as day care or respite care or exploring merits of separation or divorce. Other resources the



therapist provides is education, support and psychotherapy. From these social work frameworks, the following social intervention themes- therapy, education, loss and grief and transitional care- have emerged.

**Therapy.** Therapy is one of four social work intervention themes that is discussed throughout the literature. Some of the literature uses different approaches to therapy for the caregivers and their families. MacFarlane, (1999) thinks that marriage and therapy is quite applicable in working with TBI patients and the caregivers because of the “family trauma event” that impacts the family. The approach that is used is to address family dynamics, loss and grief and new ways of adjusting to changes that impact TBI patient, caregivers and families. Similarly, Laroi (2000) and Perlick et al., (2014) also uses the same approach in therapy to address family dynamics and new roles transition for the TBI person, caregiver and family. However, Petersen & Sanders (2015) takes the approach of only focusing on loss and grief. The loss and grief looks at the impact of the caregiver coping with the loss and addressing triggers that may come up for the caregiver. Peterson & Sanders (2015) also maintains that with this therapy technique the caregiver is more willing to accept the new TBI person and to recognize the triggers that may continue to bring up grief for the caregiver.

**Education.** Education is another social work intervention theme for caregivers and families that the literature discusses. Here the literature uses different ways in approaching these social work interventions and presenting the information to the families and the caregivers. While the educational content is similar, the approach disseminating the information varies. TBI Case Management social work treatment presents the education by oral communication, printed materials, group classes or providing web-based resources (French et al., 2011). However, Marriage and Therapy, Coping with Grief and Loss Intervention, BIFI and MFGT use a therapist

to present the education (MacFarlane, 1999; Kreutzer et al., 2010; Petersen & Sanders, 2015; Perlick et al., 2011). Two educational techniques were used, one of the being used to educate caregivers on the physical, emotional and cognitive changes that can occur with someone having a TBI (French et al., 2011; Laroi, 2000; Kreutzer et al., 2010; Petersen & Sanders, 2015; Perlick et al., 2011). The second educational technique is educating caregivers on the behavior changes that can occur with a TBI individual (French et al., 2011; Laori, 2000; Petersen & Sanders, 2015). On the other hand, Perlick et al., (2011) say the focus should be on the emotional conflict and disconnect between the caregiver and the TBI individual. By working on the emotional needs of caregivers, the therapist hopes that caregivers will be better able to problem solve. This is done by use of positive reinforcement in therapy sessions to educate partners on how to infuse coping skills in a positive way rather than negative (Perlick et al., 2011). Perlick et al., (2011) also use ecomaps as an education tool for therapists to identify the strong and weak connections within the family support system.

**Loss and grief.** Loss and grief was not a common theme in all of the literature. However, some of the literature touched on or incorporated interventions to address loss and grief for caregivers and family members. Stranberg (2009), O'Donnell et al., (2011) and Patel (2015) all noted that loss and grief shows up in the veteran with a TBI and caregivers at some point in the recovery process. MacFarlane (1999) notes that during the "mourning stage" caregivers are more willing to explore grief and are ready for help. One way to address loss and grief is for the therapist to help the caregivers emotionally through this process by validating their loss and grief in a safe environment. On the other hand, Petersen & Sanders (2015) uses five sessions to address loss and grief and incorporates journaling at the end of each session. Journaling can help the caregiver explore with free association, reflect on his or her loss and

grief and ensure self-care is being done. Caregivers and families also tell their stories of the loss and grief they have experienced with a TBI loved one. This helps make the loss real since the loved with a TBI is still living. Furthermore, Petersen & Sanders (2015) discuss that it is important during the session to understand where the sensitive areas are for caregivers and further address the sensitive areas of grief by examining it through physical, psychological, spiritual, behavioral, emotional and cognitive lens. These caregivers may have triggers that arise for them during sessions and the therapist can help with educating caregivers on their triggers. This can allow and help them cope better according to Petersen & Sanders, (2015).

**Transitional care.** The research agrees that transition of care is a part of the social work intervention process. French et al., 2011; Kreutzer et al., 2010; Perlick et al., 2011 discuss that part of the transitional care for veterans with TBI, caregivers and families is connecting them to future resources that will help with the transition back into the community. Another transition process discussed in the literature is the reintegration of a TBI loved one back into the family and the impact on the family. Caregivers might find themselves taking on additional roles or if there are children involved, the children might be part of the caretaking. Laroi (2000) also agrees that part of the transition is the TBI family member merging back into the family and the implications on the family dynamics. Laroi (2000) suggests how the family operates will depend on the adaptability and effectiveness of the transition for the TBI individual. Here the therapist takes an active role in helping the family transition and adjust to new roles in the family. On the other hand, MacFarlane (1999) suggests on-going support after the transition is made to further help caregivers with any new added challenges that may not be addressed. The literature is an agreement that some type of transitional care needs to happen. However, how the transitional care is approach does vary for each social work treatment plan.

## **Discussion**

The purpose of the systematic review was to explore what research is available on the effective interventions or social work practices for caretakers who care for a veterans TBI. In addition, the focus of this research is specific to caregivers of OEF and OIF veterans who have incurred a moderate to severe TBI. Findings in the literature recognize that caregivers need support and interventions to help them sustain caregiving a veteran of a TBI. The themes for social work interventions were education, therapy, loss and grief and transitional care. These themes were discussed through the different social work treatments that attempted to address, caregivers' burdens, depression, grief, isolation and stress. However, little research was done on the effectiveness of the themes that emerged.

### **Analysis of Therapy**

The first theme, therapy, is relevant to caregivers because of the new role of caretaking, challenges with caretaking, loss that happens with a veteran with a TBI and isolation the caregivers' may feel. MacFarlane (1999) looks at the marriage and family lens of therapy and addresses how someone with a TBI will impact the family, the adjustment stages that impact the family and the grief stages that impact the family. Other literature ignores these important stages and how the caregiver may cope with these stages or does not even acknowledge these stages as valid. Petersen & Sanders (2015) uses journaling in therapy as a tool for the caregivers to honor their process of loss and grief and changes with a TBI person. Petersen & Sander's (2015) approach to journaling after each session also helps the caregivers reflect on each process and incorporate what they have learned and how it has affected them personally.

Another important process of therapy is for caregiver to be heard and validated in therapy. TBI is a complex injury that is hidden and can be overwhelming. If the therapist acknowledges that in treating the veteran is complex, caregiving can be equally seen as complex. For example, caregivers experience complex feelings such as guilt, frustration, and being overwhelmed and these feelings need to be addressed in therapy. Another underlying feeling for caregivers when dealing with complicated grief with a TBI veteran, is that they “should be grateful” their loved one is alive (O’Donnell et al., 2011). Therapists also need to address this ambiguous loss that may arise. While therapy is a good starting point, other therapeutic models should be looked at to address the different types of caregivers such as a model for caregivers with children, spouse caregivers, sibling caregivers and parent caregivers. Furthermore, therapy can help the caregiver incorporate health coping strategies that can prevent caregiver burnout (Diaconescu, 2015).

### **Analysis of Education**

The second theme, education, was noted in every social work framework discussed which were TBI Case Management, TBI Schematic Therapy, MFGT, BIFI, Loss and Grief Intervention, and Marriage and Family Therapy (French et al., 2011; Laroi, 2000; Kreutzer et al., 2010; Petersen & Sanders; 2015; Perlick et al., 2014). While education about the effects of a TBI such as emotional, physical, cognitive and behavior is important, it is also important to address coping strategies with these challenges. There was not enough substantial information that the education that was used helped caregivers. Another aspect that was missing from the education was PTSD and the comorbidity challenges with TBI. PTSD and TBI both should be integrated in the educational processes to note the similarities of the behaviors and impacts it has on the veteran with a TBI. Lastly, there should be a follow up to see if there is any additional

education needed for the caregiver. Education may also need to be on-going for caregivers as things change with a veteran with TBI. The education could help refresh the caregiver on noticeable changes that occur overtime or reinforce what they have learned with personal experience.

### **Analysis of Loss and Grief**

The third theme, loss and grief, was only addressed in a few of the social work theory frameworks. Loss and grief should be a part of social work intervention for caregivers of a veteran with a TBI. Research shows that change in a veteran with moderate to severe TBI is a high probability rate (Patel, 2015). Other aspects of loss and grief are not only limited to the change in the veteran with a TBI but the change in the family's role and structure. Petersen & Sanders (2015) goes in depth with loss and grief in the social work framework. Also, the social work framework has a screening process to ensure caregivers are ready for this step. Another aspect that is helpful is that there is a social worker and "experienced family member" (Petersen & Sanders, 2015). While it is important to have a social worker with loss and grief that is trained, there is value in having an "experienced family member" who can share first-hand what it is like to have a loved one with a TBI (Petersen & Sanders, 2015). If loss and grief are not addressed in the social work interventions, there should be a referral program for the caregiver at some point when the caregiver is ready for additional help in coping with loss and grief.

### **Analysis of Transitional Care**

The fourth theme, transitional care, was addressed in every social work framework. This social work intervention was mentioned as transitional care as it relates to connecting to other resources after initial care. Different approaches used for transitional care was advocated within the literature. Both approaches of connecting to resources after initial care and transitional care

in the family structure should be used for the caregiver. Being connected to resources can assist the caregiver in coping with additional problems that may arise in caring for a TBI veteran.

Adjusting for the caregiver and the veteran with a TBI may take time and lack of support in the community setting may present barriers. Isolation for the caregiver can happen if the community is unable to provide applicable and adequate resources.

### **Support Service Gaps**

One area that stood out in the research was the high percentage that showed caregivers not receiving support services. This statistic elicits further questions, research and understanding by the social work field about caregivers. There appears to be a gap with this population that needs a clearer picture of why these caregivers are not using or receiving support services. Upon further analysis, some considerations for why this number may be high is the complexity of care of the veteran with a TBI and impact on the caregiver, exclusion from military population, lack of knowledge about military populations in civilian social work, challenges for caregivers with limited services provided, accessibility and time to access services. Other factors that are to be considered are continuing or expanding support services, costs and current and future legislation both federal and state level.

**Complexity of TBI and impact on caregivers.** First, support services may not be accessed because the complexity of moderate to severe TBI with veterans can be overwhelming to handle for caregivers. Since there are multiple medical disciplines involved in initial and future care for the veteran with a TBI, caregivers may struggle with keeping up with care for the veteran or managing and coordinating on-going care (Patel, 2015). In addition, unlike professionals, these caregivers have no specialized training. A question that should be asked is: is it fair to expect these caregivers to continue the care of these veterans with TBI without any

support? We know in the social work field that social workers and other professionals have on-going training to address the issues with a veteran who has a TBI. However, caregivers have no professional training and are more involved emotionally with the veteran with a TBI. Another factor in long-term care is that even if the caregiver is equipped and understands the implications of long-term care with a veteran who has a TBI, caregiver burnout may happen at some point. Some of the research shows that professional caregivers experience burnout if it is not monitored or addressed. In addition, caregiver burnout can impact non-professional caregivers too (Katsifaraki & Wood, 2014).

**Exclusion from military population.** The second reason support services may not be accessed by caregiver is the possibility of the exclusion from the military population. Caregivers that are not directly related to veterans and may not be considered family and excluded. The impact on these caregivers may not being able to access the same supports as caregivers who are directly related to veterans. Another exclusion influence is that the civilian population today are not as connected to the military population since 9/11 (Patel, 2015) . Research has shown that the military families silently deal with the challenges of deployments, returning veterans with physical and mental health issues and that there is a lack of support within the civilian communities (MacLean, 2014).

**Civilian social work education gaps.** The third gap in support services is related to social work field lack of knowledge about veterans, families and caregivers. Some of the earlier mentioned social work treatments and interventions appear to target the same issues in military to civilian populations. Even though many of these treatments may appear to work with both populations, social work field needs to recognize and address the impact on military and civilian cultures. Some of the differences include military caregivers and families dealing with



deployments, secondary trauma, on-going grief and loss when the veterans leave and come back from deployments, impact on children whose parents leave for long periods of time, comorbid challenges with the veteran and exposure to war. On the other hand, civilian populations, the impact is limited to how the patient incurred a TBI and the challenges of change within the family, changes with the TBI patient, loss and grief and ambiguous loss of the family member with a TBI. The social work field is called to educate themselves to work with military populations. Furthermore, the military population will impact the civilian social work field at some point (Canfield & Weiss, 2015). Some course work is being offered in the school settings to help social workers be prepared to address the unique challenges these veterans and families face including TBI, PTSD and caregiver needs (Sable & Osborne 2012). However, there still is a need in the social field to understand, collaborate, educate, research and to continue to help facilitate services geared towards military caregivers and families.

**Accessibility and challenges for caregivers.** The fourth reason for a gap in support services is that caregivers may not have time or resources to access support services. If the veteran with a TBI requires a lot of care, it may be hard for caregivers to give time for their own care. In addition, research shows that caregivers take on a lot of responsibilities with veterans. Some of those responsibilities include helping with emotional issues, navigating health care for the veteran, making medical appointments, working with them in therapy and assisting with aided devices (Griffin et al., 2012). In addition to regular life challenges, these caregivers may be too fatigued and stressed to have time to access support services. Furthermore, most of the services that are offered may be limited to how many people can be served at one time and where the services are located.

**Costs and legislation.** In addition to caregivers needing adequate support services, there is incurring costs of 3 billion unpaid care that caregivers give each year (Ramchand et al., 2014). More legislation and financial supports need to continue to help veterans, caregivers and families ease the burden of these costs. A bill called the Lifespan Act bill was passed in 2006 at the federal level. The bill initially was to spend up to \$53.3 million fiscally.

The bill's purpose was to provide: lifespan respite care programs at the state and local levels, planned and emergency respite care for family, training/recruitment of respite workers and volunteers, provision of information to caregivers about respite/support services, assistance for caregivers gaining access to such services and establishment of a National Resource Center on Lifespan Care (American Psychological Association, nd, para 2).

Despite the bill being passed, the bill was never funded. Later, there was bill back in 2010 called Caregivers and Veterans Omnibus Health Services Act of 2010 that was signed by President Obama (Patel, 2015). From the bill, the Caregiver Support Program (CSP) was developed (Patel, 2015). This bill funded post 9/11 seriously injured veterans' caregivers, which included a stipend, health insurance, numerous supports services including counseling, psychoeducational telephone support, web based support, peer support, counseling respite and homemaker care (Patel, 2015). The hope was to provide financial relief, better services for veterans with TBI and help caregivers and families. This new bill was a small part of the \$3 billion in costs caregivers incurred. The question now is will legislation revisit the Lifespan Act to ensure caregivers are still getting support and help other caregivers who are still carrying the financial burdens with no support.

While the literature attempts to address the caregivers' burden, stress, depression or isolation that can occur, more studies are needed to address the impact of the interventions that are being used to see if they are effective. In working with caregivers, it is important to be in tune with what is working and what is not working for them. In addition, the caregivers may not always be able to express some of the challenges that they face in caring for a veteran with a TBI. Furthermore, not all caregivers will respond the same way to long-term care. It is important to note that there is a spectrum of how much help each caregiver may need to support the veteran with a TBI. The conceptual framework mentioned, person-in-environment theory suggests that "human agency and "social structure" impact who individually responds and, in this case, how the caregiver responds (Kronrat, 2002). Depending on the environment, family supports and adaptability of the caregiver will determine how much support and services the caregiver may need.

### **Limitations**

One limitation of this research is that there were few resources available to answer the question: what are the effective social work practices that support caregivers with a veteran who has a TBI. This perhaps due to the smaller military population in Minnesota. There may be other studies at other universities that work more directly with the military population. However, in working with the librarian, all databases that were accessible at St. Catherine's were used. When the material overlapped and repeated the same information, the researcher knew this was an indication that the research was complete. Databases used were SocINDEX, PubMed, PILOTS, Academic Premier, PsychINFO and Social Abstracts. In addition, much of the research that was available in the 11 articles had authors using the same research.

Another limitation derives from the nature of the research- systematic review. The research only captured some of the social work treatments and interventions. There was no substantial data to ensure or measure if these treatments and interventions were effective. However, the systematic review gave a good baseline of what research has been done and what further research needs to be done. This research discusses types of treatments and interventions being used with caregivers. It also noted that acute care for caregivers was somewhat effective and that there is need for more longitudinal studies of the impact on caregivers.

### **Further Recommendations**

There is a need for more qualitative and quantitative research on the social work treatments of TBI Case Management, TBI Schematic Therapy, MFGT, BIFI and Loss and Grief Intervention and Marriage and Family Therapy. In addition, social work interventions of education, therapy and transitional care need to be evaluated to ensure these interventions that are used repeatedly are effective for caregivers. There also needs to be a selection of different treatments available for caregivers as caregivers may experience different issues with veterans with TBI based on caregivers' adaptability and skills. Also, the social work field needs to consider that there is a spectrum of how caregivers will individually face the challenges of caring for veterans with a TBI. Not all caregivers will respond the same. Lastly, there is need for the long-term implications that veterans with a TBI face. This will not only impact the veteran but will impact the caregiver. Finally, more research needs to be done to address the additional challenges these caregivers may face with veterans who age with a TBI.

### **Conclusion**

Only recently has the social work field area started to look at the social work treatments and interventions for caregivers who care for veterans with TBI. The survival rates are better

than decades ago and now there are other concerns that have emerged: The treatment of veterans and the treatment of the caregivers. Since the caregivers are an important factor in the veteran's quality of life after having a TBI, the roles of the family structure and family functions are now being considered. Social work needs to continue to address caregiver burden, stress, isolation and depression. Finally, if we do not take care of these caregivers, there will be untold impact on the systems of social work, institutions and government, but most importantly the on the caregivers.

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**Appendix A**

## Included Articles and Summary

Database	Title	Authors	Summary
PsycINFO	Adults with Acquired Traumatic Brain Injury: Experiences of a changeover process and consequences in everyday life	Strandberg, 2009	Civilian caregivers experiences with TBI with anger and grief
	Mild traumatic brain injury: implications for social work research and practice with civilian and military populations	Moore, 2013	Types of injuries that veterans can incur with a TBI and other diagnoses
SocINDEX	Caregivers of veterans with “invisible” injuries: What we know and implications for social work practice	Patel, 2015	Overview of TBI veterans challenges and caregivers challenges in taking care of veterans, discusses stigmas in the military
	Treating brain-injured clients and their families.	MacFarlane, 1999	TBI screening, Effects on TBI individuals and caregivers, grief and loss-civilian
	Trauma Spectrum disorders: Emerging perspectives on the impact on military and veteran families	O'Donnell et al., 2011	Uses term “Trauma Spectrum” when referring to TBI, military focus, barriers for caregivers and stigmas-military

Database	Title	Authors	Summary
Academic Search Premier	Care Coordination in Military Traumatic Brain Injury	French et al., 2011	TBI case management which helps TBI veterans and caregivers manage many challenges with having a TBI-military
	Caregiving and Traumatic Brain Injury: Coping with grief and loss.	Petersen & Sanders, 2015	Caregiving and Traumatic Brain Injury: Coping with grief and loss.
	Basic training for building a program in military social work.	Sable & Osborne, 2012	Distinction in TBI symptoms versus mental health symptoms and how misdiagnoses can occur
	Quality of professional services following Traumatic Brain Injury: Adult sibling perspectives.	Degeneffe et al., 2015	
	Psychiatric diagnoses among Iraq and Afghanistan war veterans screened for deployment-related traumatic brain injury	Carlson et al., 2010	TBI assessment at the VA starting in April 2009 screening, multiple diagnoses for veterans with TBI-military
	Tell Me What You Don't Remember": Care-Seeking Facilitators and Barriers in the Decade Following Repetitive Blast Exposure Among Army Combat Veterans	Chase et al., 2016  Tam, 2015	Veterans exposed to blasts, Attitudes that effect seeking treatment, military system experiences, health care and caregivers challenges

Database	Title	Authors	Summary
	The experience of challenging behaviours following severe TBI: a family perspective	Hanks et al., 2007	Themes reflected significant impact to challenging behaviors for caregivers living - with a TBI person for 17 years-civilian
	Caregiving appraisal after traumatic brain injury: The effects of functional status, coping style, social support and family functioning.		

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